

A MATTER OF ADJUSTMENT: A PERSONAL REACTION TO A VISION LOSS

Ted Perle

With an Introduction by Sam Genensky

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INTRODUCTION

About a year ago Hu Moshin and I urged Ted Perle to write down his personal experiences with a sequence of visual losses, the problems these losses engendered and his solutions or compromises with them. I believe that Ted's story will act as an inspiration to many visually impaired people and will provide the fully sighted reader with a better insight into how a young person feels and reacts to reductions in vision.

Sam Genensky



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Anyone holding a job brings with him to his work a set of highly personalized experiences that influence his daily performance. As a teacher of visually impaired children, I, too, have brought these experiences to my work. Prominent among them is the experience of becoming visually impaired and the subsequent experience of living as a visually impaired individual. This paper will attempt to explain what the visually impaired experience has been for me and how it has influenced my performance as a teacher of visually impaired children.

The root of my visual impairment lies in premature birth on May 31, 1948, and subsequent incubation. This occurred in New York City. No definite medical explanation has been given either to my family or to me as to why my mother delivered at the end of the sixth month of pregnancy. However, maternal speculation attributes my premature birth to two possible factors--a fall on an icy platform or excessive lifting of heavy objects during pregnancy.

My weight at birth was two pounds, twelve ounces. But that weight soon dropped to two pounds, four ounces. I was placed in an incubator and remained there until mid-June. This resulted in exposure to a level of oxygen within the incubator that proved to be injurious to my visual development. It brought on retrolental fibroplasia (RLF), then a common cause of blindness. I was lucky, because my RLF was not as serious as it might have been--but nevertheless it did result in visual underdevelopment.

I was indeed quite fortunate to have an appreciable amount of residual vision. However, high myopia in both eyes, a severe cross in the right eye, and an acuity defect and cross in the left eye were the observable results of

RLF. A latent retinal defect, later the cause of further vision loss, was also present.

It is notable that the cross in both eyes was "left alone" by my ophthalmologists who believed that it would resolve itself with physical growth. The decision to allow the strabismus to resolve itself entailed avoidance of any visual aids during infancy and early childhood. Thus, I did not wear glasses until age four and one-half.

The fact that I did not wear glasses during early childhood caused me to have a slight fear of people, because I could not see them until they were literally on top of me. This, coupled with the fact that, for the first seven years of my life, we lived ten stories above street level in New York City, made it very difficult for me to go down to the street and play with other children. Thus, I was not a very social child.

My parents sent me to a nursery school at age four to meet other children and, hopefully, to lose my fear of encountering other people. Enrollment in nursery school also represented a step by my mother to counter the influence of an excessively overprotecting maternal grandfather. Thus, my parents' decision to send me to nursery school not only represented a desire by them to have me interact with other people, but also proved to be an important step towards my emotional independence and self-awareness.

At the nursery school, I was known as a "bookworm.". I neither know why nor remember how I learned to read at the age of three and one-half. I do, however, remember being attracted to the bright red covers of Time in my paternal grandparents' home and also remember a high degree of verbalization between my parents and me.

When I was seven, the family moved to our "new world"--California. We lived in a one-story apartment for nine months before moving into our own house. Living in a one-story apartment enabled my brother and me to go outdoors almost at will, which was impossible in New York City. Freedom of movement also brought me into contact with children who accepted me as a playmate rather than rejected me as the funny kid who could not see well. "New world" indeed--for in California I fully began to experience the joys of real, spontaneous friendship with other children.

The rest of my childhood was quite normal. I remained a "bookworm" to those who knew me, because I usually read everything I could get my hands on. I was the class "student," lumped in by my contemporaries with the crowd that always received good grades--which I did.

However, good grades did not fully give me the self-assurance which any child needs. As many other children do, I wanted to emulate my father, an accomplished athlete. I also viewed athletic success as the road to playground "respect." My vision, although within the "normal" boundaries, nevertheless affected eye-hand coordination to the point where major athletic success was unattainable for me.

My parents, especially my father, were very understanding about this matter. Dad explained to me that athletes were a part of, rather than a panacea in, life. I would, he said, rely on brains rather than brawn to fashion a career. Added to this advice were swimming lessons, designed to teach me a skill at which I could and did become proficient. Here, then, was the beginning of a consciously positive attitude that I now stress when I work with my students; YOU ARE A UNIQUE PERSON WHO HAS THE POTENTIAL TO DEVELOP A SET OF UNIQUE TALENTS.

As a teacher of children who may have been psychologically rejected by their parents because of their physical or mental "imperfections," I now realize the importance of my parents' logical and loving attitude.

A positive attitude asserted itself more and more during childhood, and I gradually overcame the desire to be someone I could not be. I had a considerable reputation around school as the kid who knew nearly everything about major league sports, made good grades, and read books that neither could nor should not have been read by elementary school students.

In 1962 I entered high school, knowing that I would attend college in pursuit of a career. I continued to read as avidly as I had in elementary school. I also achieved a minor measure of athletic success by playing football while in junior high school, by swimming on the team at the local swim club, and by becoming one of the better street wrestlers in the neighborhood. In short, I had begun to develop into what I thought a "teenager" ought to be.

Then on May 4, 1963, my latent retinal defect surfaced. I had jumped from a platform after a school assembly and landed rather hard on my feet. About an hour later, while eating lunch under a tree with my friends, vision in my right eye became blurred. I cleaned my glasses, but the blurred vision did not abate. It was still there when I came home from school, and I became frightened that I was going blind.

I told my mother what happened, and we immediately went to an ophthalmologist in Whittier, my home town. He sent us to a retinal specialist at UCLA, Dr. Glenn O. Dayton, Jr., with whom it seemed I spent the next fortnight. He determined that a case of retinoschisis, i.e., a series of tears within the retina, had developed.

The minute nature of these tears prevented any corrective surgery. At that time, laser cauterization was in its infancy and it was felt that, in my case, photocoagulation would adversely affect too large a portion of my retina to warrant its use.

My eye had to be constantly watched because of the possibility that a retinal detachment might occur. Prevention of further retinal damage was based upon the avoidance of all situations in which the eye or head might receive a blow. In practical terms, that meant giving up all participation in contact sports. This was a tough experience for a fifteen year-old boy to handle. No longer could I dive off the high board at the swim club, play football in the street with my friends, or try out for the high school wrestling team as I had planned to do. Once again, my parents acted wisely.

With their help, I came to realize that I possessed the same degree of vision as I had before the injury. I would still be able to learn how to drive, go to college, and do most of the things other young guys were able to do-- including dating. Once more I had to realize that success in athletics, which I enjoyed, did not represent the only measure of personal success. By summer 1963, I was psychologically at ease, and life went on.

I finished high school in what, for me, was a blaze of glory. I qualified for a special summer program designed for entering high school seniors at the University of California, Santa Barbara, and there competed in classes with college students. My grades were not spectacular, but I knew from that experience that college was where I "belonged." Earlier that year, I also earned a driver's license.

Driving was my personal "emancipation proclamation." I was free to look for work in order to pay for automobile upkeep (when gasoline was cheap), and therefore free to become a Whittier Lothario when I could afford it. I drove with the caution necessary for one who had obtained a license with ophthalmological permission, and never was ticketed in three years of driving. Later I obtained my first summer job, in, of all places, a library.

My undergraduate days at California State College, Fullerton, reinforced a sense of growth and achievement. I made friends easily and my grades remained above average. The career goal of a degree, law school, and the eventual practice of law seemed to be a reality. Life was good.

Once again, however, fate dealt me a wild card that was totally unexpected. In August 1968, I left a summer job with an insurance company to accept a scholarship to a leadership training seminar at Brandeis Camp Institute in Simi Valley. On Wednesday, August 7, while in the communal lavatory, I was cleaning my glasses and holding them out in front of my face. The person at the sink next to me sneezed, which caused his arm to hit the right tailpiece of my glasses and push it into my right and more developed eye.

Once more I felt a slight sting and experienced the blurred vision which accompanies retinal hemorrhaging. I did nothing after the immediate impact, thinking that the blurred vision would clear up of its own accord, as it had in 1963. However, the blurred vision persisted, so I went into Los Angeles to see Dr. Dayton.

He informed me that the blow to the head was immaterial, as there had already been a steady but slow deterioration of the macular region of the retina. He felt that the blow had merely accelerated a process which would have occurred independently in a matter of time.

During that period, I had to wear a patch over my right eye, as slight corneal damage had been sustained from intensive examination. The confining sensation of the patch, shutting out a significant amount of vision, brought home to me the reality of a new physical state. Shock and disbelief over what had happened seemed to be a constant companion during the last half of August. What was going to happen? Would I be able to read with the same intensity as I had in the past? Would I be able to handle a career such as law with the vision I now possessed? Above all, would I be able to drive again?

I chose to see no one but family and several friends during this time. The previous spring, I had been co-founder of a chapter of a national social fraternity on the Cal-State Fullerton campus. I told my fraternity brothers that I would return to full participation within the chapter once I knew the full status of my vision. They understood, and during the next few years the fraternal organization was to play a very important part in my social life.

On August 24, the patch was removed, and it was discovered that damage to the macular area controlling central vision was greater than initially ascertained. However, I also found out that I would never be totally blind, because the left eye was beginning to compensate for the damaged right eye. Thus, I was able to continue reading and was also able to go ahead with plans for law school.

The decision to drive was left up to me. I really did not understand how serious my vision loss was until I sat behind the wheel of my car and noticed that there was a blind spot in the center of my visual field. I had to try though--and promptly drove to Cal-State Fullerton, thinking the drive would be as routine as it always had been.

I still do not understand how I made it there. On the way back, I rear-ended another vehicle just as my vision blurred momentarily. I knew then that I could not and would never again drive unless my vision was restored to its pre-August 7 level. That possibility was never to materialize.

In November, after consultation with another Los Angeles retinal specialist, Dr. Robert Abraham, my mother and I flew to Baltimore to consult with Dr. L. Harell Pierce. Dr. Pierce, one of the foremost retinal experts in the country, administered a thorough three-day examination at Johns Hopkins Hospital.

He concluded that surgery involving the use of the laser beam entailed a degree of risk overshadowing all foreseeable chances of success. Photo-coagulation, discussed earlier in this paper, also was an inappropriate surgical technique, because there now were too many tears upon the surface of the retina to be joined by the creation of new scar tissue. My hopes for restored vision went up in smoke.

Despite Dr. Pierce's hopeful assurances that the retinoschisis had apparently stabilized, and that no new perforations were likely to occur, I broke down and wept.

Wept for the vision I would never regain.

Wept for my lost independence gained through driving.

Wept for "the person I used to be," for I was now, with a visual acuity of 20/200 in the best corrected eye, "legally blind" by virtue of a nationally accepted definition of blindness.

Somehow I was able to listen to the doctor the next morning when he told me that I could resume my studies and plan for a law career as I had previously

been doing. I realized that I still could read, still had friends, and even had a girlfriend who did not mind driving. I left Baltimore benumbed but hopeful.

However, when I returned home I did not want to reenter school immediately because I wanted to "think things over." Here my parents' attitude concerning what was now a permanent disability showed itself. During an argument, my father literally pushed me out the front door and into the car to get over to Cal-State Fullerton to reregister. Both parents expected me to continue to participate in life to the fullest extent of my capabilities, just as they had when I was a child.

Nearly nine years have passed since my father so abruptly pushed me back into the world. Ironically, the toughest part of adjusting to a permanent visual loss has not been the physical adjustment to retinoschisis on a massive scale, but rather to the psychological aspect of being visually impaired.

Reducing the impairment from a physical and psychological barrier in the way of personal achievement and development to a mere but persistent inconvenience has not been easy. However, I feel that I have been able to do this.

There were many areas of anxiety that had to be balanced out. Whether these anxieties were economic, academic, or social, they stemmed from one source--the fact that I was "visually impaired" and "legally blind," therefore vastly different from "normal" society.

Initially, I resented the suggestion by a counselor on the Cal-State campus that since I was legally blind, and qualified for disability aid, I should accept such aid. My "blindness" was not the total darkness that I associated with the concept of "blind." I could read, travel about without bumping into

things, and pleasurably comment upon the passing parade of feminine pulchritude that abounded on the Fullerton campus. "Blindness" and "state disability aid" signified nothing less than a tin cup, cane, and general helplessness to me.

This particular area of anxiety was somewhat alleviated when I was assigned as a client to Mr. John Ruiz of the State Department of Vocational Rehabilitation. He was the first of many dynamic totally blind individuals I was to meet, and his advice helped me to realize that state financial aid was a way to attain full economic independence through schooling rather than permanent financial support, i.e., a "dole."

Socially, my anxiety was enhanced by a lack of mobility. Granted, the fraternity pitched in to a man and drove me when I needed to be driven places, but I wanted my independent mobility back! Before my vision loss occurred, I had gone out at will with whomever whenever I chose to. If I tired of a certain young lady's company, I literally got up and drove out of her life. What would I do now? Would girls drive for me in the Southern California ambiance where cars and "masculinity" went hand in hand? (Perish the thought, male chauvinist that I was.)

Those questions were answered in September, 1968, when I met a girl who was to become friend and then lover for the next five years. Personal academic setbacks, coupled with unrealistic gratefulness that a girl would actually go out with "visually impaired me," led to the decline and death of a potentially lifelong relationship. I know now that my negative self-concept led me to allow her to dominate the relationship. Since she drove, there developed a rather unequal say about who did what when. A possible solution to these problems would have been a reaction that a disability was not the pivotal point of a

relationship wherein two people care for each other. However, I did not fully understand this concept until subsequently a genuine relationship developed with another woman.

Academics at Cal-State Fullerton was the area within which my life was least affected by visual loss. I continued to read, using no magnification, as I merely brought reading materials close to my eyes. My left eye was now the "good" eye and bore the brunt of my visual activity. Visual operation in this manner, therefore, carried me through to graduation from Cal-State Fullerton in June 1970.

My academic performance up to that point was similar to my pre-injury academic performance, as I "turned on" to classes which interested me, and "turned off" to those which did not. Intellectually, I felt most nearly "equal" to the fully sighted world, as my command of Spanish enabled me to travel in Mexico during the summer of 1969, and a similar command of trivia enabled me to be a contestant on the nationally televised "GE College Bowl" in November 1969. This feeling of academic equality was highlighted in September 1970, by admission to law school at the University of San Diego.

Now that my career goal seemed attainable, I felt that I was on top of the world. I would study law independently, without any consideration of my visual disability, and, therefore, without use of visual aids. I would read and get through classes as I had in the past.

I was not at all prepared for the amount of reading and the precise answers demanded by law school examinations. When I found out later that I could not write a decent law school examination paper, and flunked out as a result, my dreams of "equality through career" were demolished.

Then, and not until then, did I fully realize the implications of being "disabled" and "different." I found that a positive attitude instilled in me by a combination of parental understanding and lifelong experiences was virtually gone. I hated myself for what I was--"a total failure"--and sought outside counseling through John Ruiz.

Outside counseling proved beneficial. Frank, open discussion of my negative self-concept allowed me to see that the positive attitude, acquired during childhood and maintained through most of my life, still applied to my current lifestyle. However, I had to find a new career goal.

I gave law school another try in 1971-72. I used tapes and visual aids when necessary, but found that I still could not consistently produce a decent exam. Performance indicated that the pursuit of law was not for me.

During the summer of 1972, I chose the education of impaired children as a career. My own loss and subsequent regaining of self-confidence made me realize that there were children who I could help to avoid the psychological torment that I had undergone. Another factor influencing my decision was a chance contact with an individual at a relative's funeral.

Dr. Samuel M. Genensky, director of research related to the partially sighted at The Rand Corporation and at the Santa Monica Hospital Medical Center, also helped me immensely in the regaining of a positive attitude. He had been told as a youngster that he possessed no usable vision, but despite this, used what he had to obtain a doctorate in applied mathematics from Brown University. His attitude towards life is based on a positive, vision-oriented self-concept in spite of a tremendous vision loss.

In 1973, my classroom work in education at California State University, Los Angeles, terminated and my student teaching began. Participation in a

career had never been closer, nor had it been at a more practical level. Nevertheless, when I mentioned that I was "partially sighted," the faculty at the site where I taught expressed "concern" about my teaching ability. I had to lead through action, and demonstrate that class control was not achieved solely through eye contact, but also through use of voice, humor, a bit of charisma, and a genuine concern for students within the class. My recommendations after the elementary school experience were generally good, with favorable comments on my teaching of elementary social studies, English, and science.

My student teaching within the field of visually impaired education was initially strange. I was up against a "protector," a young lady who believed that blind and visually impaired students should be taught rather than teach. Her unspoken (and finally spoken) attitude was, "there is just so much you can do--and a lot you can't and never will do." Luckily, my supervisor picked up on this negative attitude of my "master" teacher and placed me with a more objective master teacher in another student teaching experience.

This subsequent student teaching experience led, in June 1974, to a credential in both elementary and visually impaired education. Entrance into the "big bad world," with its triumphs and pitfalls, was now a reality. Where would the paychecks come from?

In September, they started coming in from a part-time job at Los Angeles City College, where I worked in a resource center for visually and physically impaired students. Here, teaching styles and strategies, although different from those used with younger students, had a characteristic in common with them, namely, that each student was dealt with individually. The resource person served as teacher, counselor, tutor, and facilitator, depending on the student's individual needs.

During a job interview in November 1974, with the Orange Unified School District, my current employer, we discussed individual programs in greater depth. The interview led not only to a job but also to a personal realization that seemingly insurmountable problems, such as the inability to drive within an itinerant situation, were not all insurmountable.

Itinerant teaching for me was to involve moving between seven school sites, and the interviewing administrator was concerned with how a non-driver would accomplish this. I replied that transportation was a private matter and in my case, could be solved by the use of cars, buses, or a private driver. A private driver, obtained through an advertisement in the classified section of local newspapers, has been with me for two years.

The children in my school district's visually impaired program are enrolled in the regular classroom program of instruction on a nearly full-time basis. Personal contact with teachers and administrators, who work with "normal" children, has caused them to discard their concept of the visually impaired as "helpless" individuals. Belief in human potential by these people has spurred the district's visually impaired students on to an above average in-school performance. Among the apparently successful students are an accomplished high school actor, a set of grade school students who show a zest for virtually everything they do, and a totally blind child with Down's Syndrome who easily finds his way around his school site.

I know that my visual impairment is a part of my life. I also realize that there are times when the old jinx of "proving" myself to the world--and ultimately to myself--still plays with my emotions. I now know, though, that my need to "prove" myself is fleeting due, perhaps, to what I think I have done in living with my visual disability.

Would I change things? Sure, I'd love to drive again, but until the day that can again be a reality, I'm quite pleased with life as it is. It took a while though, to arrive at this time and place in life.

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